

# SIOP Working Committee on Psychosocial Issues in Pediatric Oncology: Guidelines for Communication of the Diagnosis

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This is the fourth official document of the SIOP Working Committee on psychosocial issues in pediatric oncology constituted in 1991. This document develops another topic discussed and approved by the SIOP Committee: “communication of the diagnosis” is addressed to the pediatric oncology community as guidelines that could be followed. The highly stressful nature of the diagnostic period must be acknowledged, and com-

munication involving the staff and all family members should cover both medical and psychosocial issues. A well-planned and extensive initial session should be followed by continuing discussions. The goal is a knowledgeable family that can talk openly with its members and with the staff. *Med. Pediatr. Oncol.* 28:382–385, 1997.

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## INTRODUCTION

The diagnosis of childhood cancer is very dramatic and stressful. Communication of the diagnosis must be more than a one-time event, it should be the first step in a communicative process and relationship that involves all the medical care team members and the family that grows and changes over time. It is a process that must be repeated: what is very hard to talk about at first may get easier over time; and what can be shared and heard at first may expand, as everyone is ready for more detailed information later. It serves as a model for all future interchanges of information between medical professionals and families and between family members themselves, especially between parent and child. We can not tell people to be open and honest; we have to show them and there is no better time than at the very beginning.

Management of this communicative process has important influence on how all involved—child, parents, other family members, and medical staff—work and care for the child together.

At diagnosis the child and family's level of anxiety is very high, and their level of prior information and understanding varies greatly. Most parents want to know as much as possible about the disease, treatment procedures, prognosis, practical coping details, and emotional impacts. The staff's communication of the diagnosis and treatment plan should be done in a way that is responsive to these needs, and that develops confidence and trust among the pediatric cancer staff, patient and family. So this meeting cannot and should not be delegated to house

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officers, who may or may not do it well, but who will certainly disappear in a month or two.

With this in mind, the SIOP Psychosocial Committee dedicated the meeting in Montevideo (October 1995) to the different centers' modalities for "communicating the diagnosis". This issue forms one of the topics reported in the first official document of this group (published in the section "Critical Commentary" in *Med Ped. Oncol.* 21: 267, 1993). In Montevideo a general consensus was reached following 10 oral presentations from different world centers and a large plenary discussion, on how to communicate the diagnosis to the family and the child. It was considered mandatory to have a well-defined and planned modality of approaching this issue.

The program should include the following matters:

### WHAT VARIOUS PARTIES BRING TO THE COMMUNICATION OF THE DIAGNOSIS

a) *Parents and family members* are seldom prepared for the diagnosis of childhood cancer regardless of the presenting symptoms. Thus, it is important for them to "realize" this new reality, and to understand the medical progress that has been made in treating and potentially curing this disease.

Parents need to know who will be treating their child, to be assured of the staff's competence, and to have no doubts about the staff's and their own abilities to offer the best physical and emotional support to their child. Given the shocking and stressful nature of this early diagnostic period, it is common for parents to forget much of the information shared with them at an initial session. Thus, having continuous informal and open communication during the course of therapy is crucial.

Parents must plan, and be helped to plan, how to best use their own emotional and material resources and energies to deal with the disease and its treatment. This often involves converting their fears and vulnerabilities (like anxiety, fear of the unknown, guilt, mistrust, misinformation, and apprehension over siblings, finances and work) to a positive outlook and maintaining as "normal" a lifestyle as possible in the face of extraordinary demands. At the same time, parents must be prepared for changes in their family roles and relationships that occur as a result of extended treatment, hospitalization, and new emotional and social demands. The strength parents can offer includes patient advocacy, cooperation, help for the treatment team, and reassurance for the child patient.

b) *Children* diagnosed with cancer need to understand, in an age-appropriate manner, the new dimension of life which they have entered. They must be informed about the nature of their disease and treatment, the potential for side-effects as well as cure, and the possibility of pain and discomfort. Such information will help them maintain trust in their parents and develop trust in the medical team members caring for them.

Most children wish to be dealt with compassionately and sensitively by the staff, but also with adequate information and mutual respect that diminishes the "mystery" of the disease. Children also will be concerned about maintaining a relatively "normal" life style, and staying in touch with other family members, peers, and schoolmates. Their vulnerabilities are fear, fatigue, problems of adjustment to the hospital environment, separation and pain; and their strengths include resiliency, tolerance, good humor, and confidence.

c) *The medical staff* often brings their own anxiety and discomfort to the diagnostic event as they must share complex and painful information with "strangers". They must quickly discover enough about the child and family so that they can share information fully and appropriately. While they seek to model an open and trusting communication process, they must also often deal with overwork and time pressures, demands of research protocols and normal questions about the best treatment for individual children (randomization, proper protocol selections. . . ) The staff strengths are, of course, their expertise caring and ability to place the patient's priorities above their own.

### GUIDELINES FOR AN EFFECTIVE COMMUNICATIVE PROCESS

Our general view is that full and open communication between the medical care team and the family (including the child), and within the entire family, is the ideal situation. However, this is not always possible or preferable, and the guidelines that follow must be adapted to fit the needs and resources of each party to the communication of the diagnosis. It also must be done in a way that is sensitive to different cultural styles and preferences.

#### For parents:

1. It is important for each Center and Pediatric Oncology staff to *design a protocol for the "communication of the diagnosis"*, so that all staff members will be on the same page during this difficult time. This protocol, which can be adapted to suit particular circumstances, should draw upon a consensus of the views and experiences of different health care team members (physicians, psychologists, social workers, nurses) as well as experienced parents.

2. Immediately at diagnosis, even though some diagnostic details may be lacking, a preliminary session should occur with parents at which basic information about the diagnosis and treatment should be shared and parents' questions and concerns solicited. It should be emphasized at this time that a more relevant communicative session explaining the complete "project of cure" will soon follow and that varied health care team members and other family members may attend it. The communication can be accompanied by a written text or au-

diotape containing essential information about both the disease and the prognosis. Later, more informal and unstructured meetings should check the relevance and utility of the information first shared, and discuss in greater detail treatment plans, diagnostic and prognostic markers, changes in the child's status, family and environmental issues, etc.

3. The communicative session should be conducted in a private space, with comfortable seating and an environment conducive to discussion of painful issues. Both parents and the chairman or a senior medical staff member should be present, as well as the head nurse or another staff member. The attendance of the family's local physician should be encouraged unless parents do not agree. If requested the child with cancer (according to age), other family members (e.g. grandparents: they are significant sufferers that often receive little attention!) or close friends also may attend this session.

4. The communication should include an overview of the disease, the types of therapy relevant to the child's illness, and the general prognosis.

5. In following meetings information (and even suggestions) can be provided regarding daily activities such as: monitoring medication, maintaining a "normal" lifestyle for the family and child, the child's continuing involvement in school and peer activities, dealing with hope or fear and realistic caution, family dynamics (e.g. spousal, division of roles, sibling concerns), the child's peer relations (awkwardness, teasing), and practical problems (hospital transportation, insurance and finances).

6. It also is useful to link parents immediately with other parents of children with cancer or a parent support group, so that if they wish they may utilize this source of information and support.

#### **For the child:**

1. A similar protocol for the conduct of communication sessions with the child should be developed, with attention paid to variations in the child's age and developmental level.

2. Staff communication should elicit questions and concerns from the child with cancer as well as provide information to the child. In this way the staff can demonstrate trust and respect for the child's intellectual and emotional needs and resources, and engage them in coping actively with their situation.

3. A staff member skilled in medical communication and interpersonal relationships should talk directly and separately with the child about these issues. Thus, we acknowledge that every physician may not be the staff member best able to conduct this session, although this guide should not be interpreted as removing physicians from direct communicative responsibility. A separate session with the child permits particular concerns to be

raised and discussed that the child initially may be reluctant to share with her/his parents, or vice versa. Subsequently, some of these issues may be able to be discussed in a total family situation. Total and inclusive family conversation is critical, but cannot be forced or imposed upon the family by the staff. After the child receives the diagnosis, he/she should be encouraged to talk with his/her parents about the disease and treatment.

4. Communication with the child should focus on explaining the disease and its treatments, realistic discussion of potential side effects as well as long-term cure, and various interpersonal or social issues. If the staff can open conversation with the child about family and peer relationships or concerns, it is more likely that the child and family will face any emerging issues squarely and confidently, and be prepared to ask for assistance or support when necessary.

5. With the child and parents' approval, the staff also may conduct informational sessions with extended family members, the child's peer group, school classmates, and teachers.

#### **FINAL COMMENT**

These general guidelines must be interpreted and applied in the context of the prevailing cultural assumptions, medical situations, family dynamics, also resources and abilities of the parents, children and staff members involved. Indeed different cultures and nations have very different views of what information is appropriate to share between staff members, parents, and children. Moreover, family structures vary enormously, so that "who is the family" may vary in different nations and social classes. The age and educational level of the child will affect the extent and timing of the information that can effectively be shared with her/him.

However, these guidelines offer the best hope for providing full information to the family, encouraging a mutually respectful and trusting relationship that permits the child and parents to raise their concerns and questions, and empowering staff, parents and children to be wiser and fuller partners in the care of the child with cancer (Table).

#### **SUMMARY TABLE OF ESSENTIAL POINTS: Principles for Communicating the Diagnosis**

1. Establish a protocol for communication.
2. Communicate immediately at diagnosis and follow up later.
3. Communicate in a private and comfortable space.
4. Communicate with both parents, and other family members if desired.
5. Hold a separate session with the child.
6. Solicit questions from parents and child.
7. Communicate in ways that are sensitive to cultural differences.
8. Share information about the diagnosis and the plan for cure.
9. Share information on lifestyle and psychosocial issues.
10. Encourage the entire family to talk together.

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